

**Adult Daughters Caring for Their Elderly Mothers With Dementia:  
Impact of Prior Relationship on Caregiver Burden**

Kathleen Coletti, D.S.W.  
D.S.W., Adelphi University, 1997  
Senior Social Worker, Woodside Adult Day Care  
Wyckoff, New Jersey

Statement of the Research Problem

The substantial demographic and socioeconomic changes that continue to take place in society have created an increasing need for caregivers to deal with the growing population of disabled elderly. Currently, there are approximately 33.2 million people aged 65 years and older who constitute about 13% of the total population (United States Department of Commerce, 1994). This segment of the population is expected to grow to 79 million (20.6% of the total population) by the middle of the next century. Moreover, those who are over the age of 85, known as the "oldest old" are the fastest growing segment of the population and are expected to double in size by the year 2020 (United States Bureau of the Census, 1992).

These factors, coupled with the converging demographic trend of a diminishing birth rate, have set the groundwork for a societal crisis of significant proportion. There are suggestions by some experts that the need for long term care of the elderly "may well be the major health and social issue of the next four decades, polarizing society over the next twenty to forty years" (Vogel & Palmer, 1982, p. 5).

The resultant economic impact on society in caring for so many of its disabled elderly is staggering, particularly in the face of ever diminishing financial resources. In their role as primary caregivers, women family members are frequently instrumental in averting the often inevitable and costly option of institutionalization of this portion of the elderly population. While women's ability to take on this responsibility for their elderly family members may constitute significant benefit to society, it does not come without considerable psychological and physical cost to these caregivers. Consequently, an extensive amount of research over the past two decades has focused on caregiver issues and needs. In particular, there has been some recognition that middle-aged women have been granted the often unanticipated charge of caring for the elderly (Abel, 1990; Barber, 1988; Cicirelli, 1993; Horowitz, 1985; Mui, 1995; Parks & Pilisuk, 1991).

Characterizing these caregivers as "women in the middle," Elaine Brody (1981; 1991) addressed the issues of primarily middle-aged women, who, despite their increased

participation in the work force, continue in their role as primary caregivers for the elderly. The research that was undertaken here specifically focused on the burden of daughters as it is associated with their role as primary caregivers for their elderly mothers who are suffering from some form of dementia.

Despite the comprehensive research concerning the correlates of caregiver stress and burden, there has been only passing recognition, at best, of the impact of prior relational issues on current caregiver burden (Williamson & Schulz, 1990). While independent variables such as caregiver/care recipient health, role demands and social support are among the significant variables affecting caregiver stress and burden, the role of caregiving needs to be set within a larger relational and developmental context. Consistent with social work practice and theory, the knowledge of past relational history serves as an integral part of problem assessment and resolution.

### Research Questions

In their roles as maternal caregivers, daughters, may be particularly vulnerable to the burden of caregiving due to the inherently unique and intense quality of the prior relationship with their mothers (Jordan, 1991; Surrey, 1991). Therefore, in an effort to examine the complex issues involved in caregiver burden, this study sought to discover if the daughter caregivers' perceptions concerning the quality of the past relationship with their mother-care-recipient had any significant impact on caregiver burden.

Specifically, this study was designed to empirically test the hypothesis that the better the daughters' perceived quality of the past mother-daughter adult relationship, the less burden she will experience as the maternal caregiver. Additionally, the concept of caregiver role assumption or role acquisition was examined as well as the perceived presence or absence of choice in the assumption of the caregiver role. Therefore, a secondary hypothesis examined whether the manner and perceived presence of choice involved in the assumption of the caregiver role had an impact on caregiver burden.

### Methodology

This research was conducted over a period of 14 months from 1995-1996 involving a convenience sample of 52 daughter caregivers whose mothers attended nine participating Medical Adult Day Care Centers in Northern New Jersey and Rockland County, New York. These daughters were all currently co-residing and caring for their elderly mothers who had been diagnosed by a physician with some form of dementia (i.e., Alzheimer's disease, multi-infarct dementia, Parkinsonian dementia, Pick's disease, etc.). Each of the subjects was given a personal interview which consisted of a battery of instruments and some accompanying open-ended questions.

Burden, the outcome variable of this study, was viewed as the individual's subjective appraisal and reaction to those stressful life events (also referred to as stressors) that are felt by the person to be a strain on personal resources and well-being. For the purposes of this study, burden was viewed as a reaction to stress and was operationalized through the use of The Caregiver Burden Interview (Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). This scale, which is in the form of a self-report questionnaire, consists of 22 items concerning some of the caregivers' perceptions on the effects of caregiving on their psychological well-being, personal and social life, finances, and present relationship with the care-recipient. The Chronbach's alpha for internal reliability for this instrument in this study was .93.

To measure the quality of the past mother-daughter adult relationship before the onset of the dementing illness, the Dyadic Relationship Scale, which is a component of the Family Assessment Measure, was administered (Skinner, Steinhauer & Santa-Barbara, 1983). This scale has seven sub-scales measuring the dimensions of a relationship known as: task accomplishment, role performance, communication, affective expression, involvement, control and values and norms. This is a self-administered questionnaire of 42 statements that ask the respondents to decide how well each statement describes her adult relationship with her mother prior to the onset of the dementing illness. For this study, the alpha coefficient for the Dyadic Relationship Scale was .94.

In order to account for other important variables in the caregiving situation, extensive demographic material was examined as were the findings that were derived from the use of two other scales that measure caregiver/care-recipient factors. The Functional Dementia Scale (Moore, Bobula, Short & Mischel, 1983) with an added caregiver "bother" scale was used to assess both the degree of problematic behaviors associated with dementia and the caregiver's subsequent response to these behaviors. Items that are included in this scale feature major problems of dementia such as emotional lability, agitation, wandering, incontinence and memory loss. This questionnaire consisted of 20 items within three sub-scales: activities of daily living, orientation and affect, each with a Chronbach's alpha of .85, .83, and .84 respectively. Each caregiver was then asked how they experienced each of these problematic behaviors on an individual basis in terms of how much it "bothered" them. In this study, the concept of "bother" was seen as an annoyance factor that related to single tasks and behaviors that are associated with caregiving for the dementia client.

The amount of assistance required by the mothers in this sample was measured by the daughters' responses to the Activities of Daily Living Assessment (ADL) as derived from the Older Americans Resource and Services scales (Fillenbaum, 1988). Eighteen questions assessed the care-recipient's ability to engage in activities such as dressing, bathing managing money, etc. This scale was also expanded for the purposes of this study so that it measured not only how much help was given to the mother but also how much of this help was personally provided by the daughter for each activity.

The secondary hypothesis concerning role assumption was explored using several open-ended questions pertaining to the daughter assumption of the role as primary caregiver. In an effort to clarify issues of choice and motivation in assuming the caregiver role, the following questions were asked: "Were you the only one available to fulfill this role?", "Was this a role that you had always assume you would take?", "Did you feel that you had a choice in assuming this role?" and "Would you like someone else in the family to help you more with the care of your mother?"

## Findings

The major finding in this study supported the hypothesis that predicted a correlation between a better perceived past relationship and less burden. Conversely, those daughters who reported more problematic issues in their past relationship with their mothers experienced more current burden in their role as maternal caregivers. A correlational analysis of the sub-scales found in the Dyadic Relationship Scale revealed that there were significant correlations between three of the seven sub-scales and the Burden Interview.

The most significant correlation was found between the Affective Expression sub-scale of the Dyadic Relationship Scale and burden. Higher scores on this sub-scale, which indicated the caregiver's perception of a problematic issue in the past relationship, positively correlated with greater burden scores ( $r=.441, p=.001$ ). According to the test's authors, weakness in the area of affective expression can indicate insufficient expression, inhibition of (or overly intense) emotional discharge that can occur at inappropriate times (Steinhauer, Santa-Barbara & Skinner, 1984). This variable accounted for 19% of the explained variance in burden according to the Pearson correlation coefficient ( $r^2=.194$ ).

The next most significant correlation was found between the Affective Involvement sub-scale of the Dyadic Relationship Scale and burden. This variable accounted for 9% of the explained variance in burden ( $r^2=.092, p=.03$ ). Problems in this area of the relationship can indicate the absence of involvement among family members, or interest that may be seen as devoid of feeling. According to Skinner et al., problems found here may indicate involvement that can be "... narcissistic or to an extreme degree, seen as excessive or intrusive. Family members may exhibit insecurity and lack autonomy." (1991, p.20).

The Dyadic Relationship sub-scale measuring Role Performance also showed some significance in correlation with burden ( $r=.281, p=.04$ ). This variable accounted for about 9% of the explained variance in burden. Weakness in the area of role performance may indicate that there was insufficient role integration accompanied by lack of agreement concerning role definitions. Subsequently, these issues could result in role tension and

conflict. Finally, there was significant correlation found using the entire Dyadic Relationship Scale and burden ( $r=.275, p=.05$ ). This scale accounted for 8% of the variance seen in burden.

The secondary hypothesis concerning the manner and perceived presence of choice involved in the assumption of the caregiver role and the impact on burden was not supported by the findings of this study. Kruskal Wallis or Mann-Whitney test were used where appropriate to analyze burden as it was associated with the dichotomous answers to this subjective portion of the test. The caregivers' perceived presence or absence of choice in the assumption of the caregiver role did not have any impact on burden. Similarly, the other three subjective questions concerning availability of others to help, planned assumption of the caregiver role, and the desire for help were analyzed and there were no differences in burden found between those caregivers who answered negatively or positively.

### Other Findings

In addition to examining the impact of the perceived quality of the past relationship on the caregiver, other mediating variables also were taken into account. The dependent variable, burden, was studied through a multiple regression analysis using the forward selection procedure. The results of this analysis yielded a seven variable "model" of burden that accounted for 72% of the explained variance found in burden.

According to this analysis, the most significant contributor to burden involved the Activities of Daily Living sub-scale of the Functional Dementia Scale (FDS) combined with the caregiver "bother" scale. This variable accounted for 46% of the variance in burden ( $p=.0001$ ). This sub-scale was used to measure functional problems associated with dementia with the addition of a caregiver "bother" scale which assessed the extent that each of these functional disabilities disturbed the caregiver.

The next most important contributor to burden in this model involved the Orientation sub-scale of the FDS and the caregiver "bother" scale. This variable accounted for an additional 11% of the variance found in burden ( $p=.001$ ). This sub-scale measured the amount of difficulties in orientation associated with dementia and also included the extent of caregiver "bother."

The remaining four out of five variables that contributed to this model of burden were the dimensions of quality of past relationship, which were (in order of importance): affective expression, task accomplishment, affective involvement and control - sub-scales of the Dyadic Relationship Measurement. They demonstrated a combined contribution of 14% of variance found in burden. Though clearly not the most important contributors to burden, the quality of the past mother-daughter relationship still bears up as a significant

factor to consider even when other factors within the context of caregiving are taken into account.

Finally, a Pearson's correlational analysis was also done on the demographic information using the variables of age of mother, age of daughter, daughter's educational level, marital status, income, children at home, hours of employment, hours of informal help, length of caregiving, use of day care and self-assessment of health. There were no significant correlations found between these variables and burden. The only significant correlation was found between self-assessed caregiver health and burden ( $r=.31, p<.05$ ). Those daughters who reported poorer health were more likely to feel burdened.

### Implications for Social Work Practice

Caregiving is a role that is often implanted into the life course of the caregiver deriving its meaning from many sources. The fact that socio-demographic and economic variables bear no significant contribution to burden in this study, serves to reinforce the notion that there are more subtle issues to be considered. Past relational history is a factor that is often overlooked in research and practice as a significant component in the assessment of the correlates of caregiver burden. Taking this issue into account in research, assessment and intervention can lead to a more complete understanding of the individual response to the caregiving situation. It is within the context of the past relational history that we may find the meaning that the individual ascribes to the role as caregiver.

Past relational problems are obviously unalterable, however, their impact on the caregiver's subjective sense of burden and stress can be mitigated through the use of several interventional strategies. Ideally, where possible, the assignment of caregiver responsibilities should be given to someone who has had less difficulty in this area. Since selection of caregiver is rarely an option, however, professionals have to examine what is available to these caregivers in order to minimize the impact of past relational problems.

Altering the meaning of the past relationship and its impact on the present situation may be accomplished through the use of several interventive techniques. Individual counseling may be most appropriate for those who must deal with troublesome past relationship issues particularly as they contribute to self-doubt, negative self assessment and a sense of worthlessness. Daughters in this study who reported these relational problems, may be particularly vulnerable to these issues with the caregiving situation exacerbating any ongoing intrapsychic and interpersonal difficulties.

Individual and group psycho-educational approaches may be useful in providing alternative caregiver coping styles. For example, caregivers who can be educated to see difficult behaviors within the context of the dementing illness, may be more likely to respond positively with less likelihood of personalizing. Encouraging the use of

behavioral management strategies that are more successful and appropriate can lead to less conflict and frustration within the caregiving dyad. Hinrichsen and Niederehe (1994), for example, found that the use of encouragement with the dementia patient, as a behavioral management strategy, has been demonstrated to be associated with less caregiver burden and less desire to institutionalize.

Cognitively focused coping skills such as reframing the problem, acceptance and focus on the positive have been demonstrated to be associated with better emotional adjustment in the caregiving situation (Pratt & Kethley, 1988; Pruchno & Resch, 1989). Appropriate caregiver coping strategies and behavioral management skills, as they relate to issues of dementia, may help caregivers de-escalate potential conflictual and frustrating situations.

The alleviation of objective stressors is another implication of this study because of the beneficial and empowering impact it may have on the caregiver. According to the model of burden that was derived from this research, care recipient problems with activities of daily living associated with the caregivers' subsequent response (bother), was the strongest predictor of burden. This finding provides a good deal of information as to how interventions may be directed in terms of providing aid with instrumental tasks of caregiving.

As a critical component in the care of the elderly, family caregiving and its inherent challenges need to be effectively addressed on an individual and social policy level. The issues for the social work profession in working with the individual involve comprehensive assessment upon which appropriate and individualized interventions are made. The careful and informed study of the mediators of caregiver stress and burden can also reveal factors that facilitate caregiver well-being. Caregiving, despite its challenges, can also be a source of gratification. Interventions that appeal to caregiver strengths, adaptability and personal growth can empower the caregiver to seek positive solutions while enhancing well-being.

Societally, we must recognize the intense commitment and responsibilities that many caregivers, particularly women, silently endure for what is sometimes a significant portion of their own lives. This is a role for which there are no clear precedents or guidelines and therefore it presents probably one of life's greatest challenges. To best serve the ever expanding elderly population, the social work profession needs to acknowledge and support the silent efforts of the caregivers through an informed and thoughtful understanding of the conditions and issues of the past as well as the present.

## References

- Abel, E., (1990). The ambiguities of social support: Adult daughters caring for frail, elderly parents, Journal of aging studies, 3, 211-230.
- Barber, C., (1988). Correlates of subjective burden among adult sons and daughters caring for aged parents. Journal of Aging Studies, 2 (2). 133-144.
- Brody, E., (1981). "Women in the middle" and family help to older people. The Gerontologist, 5, 471- 479.
- Brody, E., (1991). Women in the middle: Their parent-care years. New York: Springer Publishing Co.
- Cicirelli, V., (1993). Attachment and obligation as daughters' motives for caregiving behavior and subsequent effect on subjective burden. Psychology and Aging, 8 (2), 144-155.
- Fillenbaum, G., (1988). The Duke Older Americans and Resources Services Procedures Multidimensional functional assessment of older adults: New Jersey: Lawrence Erlbaum Associates.
- Hinrichsen, G., Niederehe, G., (1994). Dementia management strategies and adjustment of family members of older patients. The Gerontologist, 34 (1), 95-102.
- Horowitz, A., (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist, 25 (6), 612-617.
- Jordan, J., (1991). Empathy and self boundaries. In J. Jordan, A. Kaplan, J. Miller, I. Stivers & J. Surrey (Eds.) Women's growth in connection: Writings from the Stone Center, New York: Guilford Press.
- Moore, J., Bobula, J., Short, T., & Mischel, M., (1983). A functional dementia scale. The Journal of Family Practice, 16 (3), 499-503.
- Mui, A., (1995). Caring for frail elderly parents: A comparison of adult sons and daughters. The Gerontologist, 35 (1), 86-93.
- Parks, S., Pilisuk, M., (1991). Caregiver burden: Gender and the psychological costs of caregiving. American Journal of Orthopsychiatry, 6 (4), 501-509.
- Pratt, C., & Kethley, A., (1988). Aging and family caregiving in the future: Implications for education and policy. Educational Gerontology, 14, 567-576.



- Pruchno, R., & Resch, N., (1989). Aberrant behavior and Alzheimer's disease: Mental health results on spouse caregivers. Journal of Gerontology, 44, 177-182.
- Skinner, H., Steinhauer, P., Santa-Barbara, J., (1983). The family assessment measure. Canadian Journal of Community Mental Health, 2, 91-105.
- Surrey, J., (1991). The self-in-relation: A theory of women's development. in Jordan, J., Kaplan, A., Miller, J., Stiver, I., Surrey, J.(Eds.). Women's growth in connection: Writings from the Stone Center, New York: Guilford Press.
- U.S. Bureau of the Census, (1992). Statistical Abstract of the United States. Washington, D.C., U.S. Government Printing Office.
- Vogel, R., & Palmer, H., (1982). Long-term care perspectives from research and demonstrations. Washington, D.C., U.S. Department of Health and Human Services.
- Williamson, G., & Schulz, R., (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. Psychology & Aging, 5 (4), 502-509.
- Zarit, S., Reever, K. & Bach-Peterson, J., (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20 (6), 649-655.
- Zarit, S., Todd, P., Zarit, J., (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26 (3), 260-266.